

**Responding to the Mental
and Emotional Needs
of
People with Profound and
Multiple Learning Disabilities**



Mental and Emotional Well-being

There is a growing awareness that people with profound and multiple learning disabilities (PMLD) suffer from depression, anxiety and stress, as do many other individuals. Because they cannot talk about their difficulties these may be easily overlooked by those who care for them. We also know that people with PMLD experience more health and sensory problems, which can have a direct effect on a person's well-being.

Mental health is as important as physical health. Good mental health helps people cope with day-to-day living, to enjoy life and to cope with pain, and sadness. Mental health is central to well-being. Everyone has mental health needs and these are unique to each person. When mental health needs go unmet, individuals are susceptible to developing mental health problems. It is essential that all families and carers who support people with PMLD recognise the importance of good mental health and the impact it has on overall well-being and quality of life.

Diagnosis

Diagnosing mental health problems in people with PMLD is extremely problematic because:

The following quotes illustrate each bullet point and show how some parents assess the mental and emotional state of their son or daughter.

- It is difficult to determine what a person with PMLD is feeling in order to assess his or her mental state

"I know it is difficult to describe the changes in facial expressions, because you know the changes are so subtle, but very noticeable. When she's happy you certainly know she's happy, because she sings. The tone changes with changes in her emotional and mental well-being, just a slight difference; it's like the difference between somebody singing a lament and singing something happier."

- symptoms of poor mental health may be thought to be part of the person's complex disabilities –this is called "diagnostic overshadowing"

“After a sustained period of illness, and about the time Craig was going through puberty, Craig ended up with pneumonia and he was in and out of hospital. This had a tremendous effect on Craig’s well-being and on his general state of mind. Having said that, I didn’t recognise it....I thought it was all around his health issues. What I thought was him ailing or sickening again could, I think, have been him sinking lower and lower down and absolutely being totally fed up and depressed, but I certainly wouldn’t have recognised it being that. Looking back I do, but at the time, no, I thought he was probably sickening again.”

- it may be difficult to distinguish challenging behaviour from mental ill-health, or to see the link between poor mental health and how this is expressed in challenging behaviour.

“If anybody entered the room at that time he would just take off very quickly, roaring loudly and constantly until he got to another environment that he would consider suitable, then again the staff would go back and try to interact with him, but he would cover his head with his arms completely which we took as a sign of him opting out and very much a plea to leave him alone.”

In diagnosing mental health difficulties in people with PMLD it is essential to consult with parents, other relatives or those who know the person well; only they can tell you about the changes in the person’s mood or behaviour that may indicate a mental health problem.

Factors that affect mental health

People develop mental health problems for a variety of reasons; these can be both external factors (to do with changes in the in person’s environment or the people around them); and internal factors (to do with changes in the person’s physical health, bodily changes or level of pain).

External factors

- **bereavement and loss** - is a complex process for us all and despite the fact that people with PMLD experience a lot of grief in their lives they are generally not adequately supported or helped through the grieving process. They experience loss of family members, staff members and members of their peer group. The impact of loss and bereavement on someone with PMLD can often be detected through noticing changes in patterns of behaviour or physical health. The length of time a person with PMLD takes to recover from changes affecting their emotional and mental well-being is often underestimated.
- **abuse** – whether it is physical, sexual or emotional abuse may lead to mental health problems. Abuse is more prevalent amongst people with learning disabilities, particularly those with PMLD as they find it harder to protect themselves from abuse and may not be able to tell others what is happening.
- **moving house** – or leaving the family home can also trigger changes in emotional and mental well-being. Adequate planning and preparation can help lessen the impact for someone with PMLD. Familiarising the individual with the staff who will be supporting them in their new home is crucial to preventing mental health problems.
- **transition from child to adult services** – is often underestimated and can lead to changes in emotional and mental well-being. Again, adequate planning and preparation can help lessen the impact of transition.
- **staff changes** – also have an impact on the mental and emotional well-being of individuals and this is often overlooked by those caring for individuals with PMLD
- **changes in routine** – can cause increased levels of anxiety and the impact of this is often underestimated by those supporting people with PMLD

- **parental stress** – has a major impact on the lives of the son or daughter being cared for. Families caring for a person with PMLD experience high stress levels for a variety of reasons and this can impact on the emotional well-being of the person they are caring for. No one likes to see their parents stressed and this is no different for someone with PMLD
- **lack of stimulation** – is a is a major trigger for changes in mental health.

Internal factors

- **physical illness** – people with PMLD can experience rapid changes in their physical health and this can impact on their mental well-being. Sudden changes in physical health and prolonged periods of illness are often triggers for a deterioration in a person's emotional health. For example, Gastro-oesophageal reflux (GOR) has been found to occur in 70% of people with PMLD and this is known to cause serious discomfort. If this discomfort is not resolved either behavioural problems and/or low mood can occur, see *PAMIS* eaflet on *Understanding and Managing Nutrition*
- **pain** – is another factor that causes a deterioration in mental wellbeing and the changes of behaviour that can result from the experience of pain can be significant. For example, toothache can be extremely painful and if the person is unable to communicate it may result in the person exhibiting challenging behaviour
- **medication** – can also result in changes to behaviour and to changes in mental well-being. For example, medication prescribed for the treatment of epilepsy can cause depression
- **puberty** – can cause changes to a person's emotional and mental well-being. Extra support may be needed to guide the young person through this difficult time
- **menstruation** – is often a trigger for changes in mood and behaviour and it is important to consider the impact of menstruation when looking at indicators and reasons for changes in behaviour.

The effects of changes in emotional and mental well-being will vary depending on the individual but it is important to be aware of any changes in a person's mood or behaviour that might indicate they are experiencing a deterioration in their emotional and mental well-being.

Recognising mental health problems - behaviours that might be indicators of changes in mental and emotional well-being

- **changes in appetite** – increased appetite or loss of appetite
- **changes in sleeping pattern** – someone might sleep more or less than usual
- **changes in facial expression** – frowning, not smiling, not making eye contact
- **changes in posture** – this might be sitting with their head down
- **withdrawn/lack of response** – if someone appears to be quieter than usual or does not respond in the usual manner
- **increased crying** – particularly in situations where the person was usually comfortable or happy
- **self injurious behaviour** – biting (thumb, hand), nipping, grinding teeth (if this is not the person's usual behaviour)
- **increase or decrease in normal vocalisation**
- **disruptive behaviour** – can be a result of changes in emotional and mental well-being and it is important to recognise and respond to any changes noticed
- **increase in seizure activity** – for some people an increase in seizure activity may be attributed to changes in emotional and mental well-being
- **increase in sexual behaviour** – sex is a difficult topic to discuss and what is difficult for some people can be seen as positive by other people. Cultural and religious values should be respected in supporting individuals and their families. Also, it is not unusual for any sexual expression shown by people with learning disabilities to be seen as a problem. Rarely is it celebrated as a normal aspect of development. Very often an increase in sexual behaviour can be an indicator of changes in emotional and mental well-being.

Assessment

Formally assessing mood and mental well-being in people with PMLD is difficult. The two most appropriate tests which can be used by carers to record their observations of are:

- The mini PAS-ADD (Psychiatric Assessment Schedule for Adults with a Developmental Disability) is often used but it has drawbacks as some of the questions are not relevant to people with PMLD and this may affect the results.
- The MIPQ (Mood, Interest & Pleasure Questionnaire) relies on carers to answer a number of questions, e.g. in the last two weeks, do you think the person's facial expressions look happy?

The outcomes can help families and paid carers develop individualised strategies to identify and overcome the factors that may be causing changes in mood and behaviour.

Good mental health is important for everyone and people with PMLD should be offered adequate support to ensure they receive the care necessary to ensure their emotional and mental health needs are being met. There is also a need for training for parents and carers on recognising and responding to changes in emotional and mental well-being.

References

All the references listed below are available at the *PAMIS* library – contact j.t.taylor@dundee.ac.uk or tel: 01382 385 154.

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Medical Consent

In Scotland if you are over the age of 16 you are legally an adult. The law assumes you can then make decisions about your medical treatment. People with profound a multiple learning disabilities may not be capable of giving informed consent. Under the **Adults with Incapacity Act (Scotland) Act 2000**, parents (and others) are able to apply to become **welfare guardians**. This involves an assessment of the ability of the adult concerned to make informed decisions and an application to the Sheriff's Court for a **guardianship order** to authorise a particular person to make decisions on her/his behalf.

Recommended Websites

www.learningdisabilities.org.uk

The Foundation for People with Learning Disabilities produces a range of publications, including reports, and information on mental health issues.

www.thecbf.org.uk

The Challenging Behaviour Foundation has a number of very useful factsheets and DVDs that are free of charge to families and unpaid carers.

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